

## Understanding the impact of gaps in identification and support for girls on the autism spectrum

On Tuesday 8 November 2016, a high level roundtable was held in the House of Lords to raise the profile and understanding among political stakeholders of the issues of the under-diagnosis and support of girls with autism. The event was convened by the Girls with Autism Forum, under its Chairman, Professor Barry Carpenter, CBE, and hosted by Baroness Sheila Hollins.

The ASC and Girls Forum brings together many noted experts in the field of autism, including academics, policy experts, and parent champions. While there is growing understanding that there are far more autistic girls than previously recognised, the ASC and Girls Forum believe that there are still big gaps in understanding among educational and health professionals about how to diagnose and support girls living on the autism spectrum.

Members of the forum have co-authored a nasen mini-guide, [Flying under the radar](#), a practical guide for practitioners and educationalists who want to better understand latest research and tools for supporting girls on the autism spectrum. The Forum is also holding a major conference with the National Association of Head Teachers in January called Girls on the Autism Spectrum: The Big Shout, which will look at these issues in greater detail.

The parliamentary roundtable in the House of Lords was conceived as a further critical opportunity to bring together parliamentarians, policy makers and those in the autism community to discuss the specific challenges faced by girls with autism. While the number of parliamentarians with an interest in autism more generally has increased considerably in recent years, few MPs, peers or civil servants are aware that commonly-held views on gender and autism may not be correct. The meeting heard from a number of speakers who sought to inform and educate those present about what is now known about girls and autism and how the lack of focus on this group is, in many cases, causing considerable harm, frustration and distress.

Professor Francesca Happé, Professor of Cognitive Neuroscience at the Institute of Psychiatry, King's College London shared her insights into what research looking at girls and autism has shown to date. She highlighted that although previous research estimated that approximately 4:1 males to females are affected with autism (1:10 at the high functioning end of the spectrum), more recent research has re-valuated this assumption to the degree that the ratio is thought to be perhaps only 1:2.

She highlighted that girls are diagnosed later than boys – if at all – and the diagnostic bar is far higher for a diagnosis to be made in females. Overall, she stated that there are big gaps in knowledge about girls and autism, not least because the majority of research into autism is biased towards males, with girls even specifically excluded from some studies. Furthermore, diagnostic overshadowing, in which other behaviours or health conditions are identified but autism is not considered, is a prominent issue, which hinders the diagnosis of autism being made in females.

To demonstrate the real-life impact, the meeting heard first from Carrie Grant, broadcaster and parent of three girls on the autism spectrum, who talked about the challenges and pressures faced by families with autistic girls. She outlined the battles with schools and teachers, the risk of exclusion and suspension, and noted that even with a diagnosis, half of autistic girls do not have access to the right health services to support them. She also stressed the significant toll that autism can have on a girl's mental health, and raised concern that access to mental health services can be extremely difficult – often until the girl threatens suicide.

Carrie emphasised the talents, skills and contribution that her children can offer when given the right support. She concluded by stressing the urgent need for schools and health partners to understand far more about girls with autism, as well as for the government to take a more active role in filling the policy gaps.

Lucy Barker and Beth Carboys, ex-students from Limpsfield Grange School, a special state school for girls with communication and interaction difficulties including autism, then shared their personal experiences of autism. Both stressed how valuable it has been for them to be schooled in a supportive and understanding environment. They explained the importance of early diagnosis and outlined how a lack of an early diagnosis can have huge impact in relation to the variation in quality of life experienced. It was agreed that although finding employment can be difficult for girls with autism, supportive employers who understand the adjustments that need to be made can help girls with autism to excel in the work place.

MPs, peers, councillors and other stakeholders then discussed the current situation and what could be done to improve it for the future. A number of points were raised, showing both the scale of the challenge and the opportunities for action.

It was agreed that overall, efforts have been made to improve the lives of autistic people, and that these are welcome. However, it was pointed out that there now needs to be a reappraisal of thinking using a 'gendered lens' - meaning that mainstream thinking about autism should be reconsidered to recognise that it may be missing or excluding the needs of girls. It was argued that without a dedicated focus on girls, the existing bias towards viewing autism as a male condition will be sustained.

The different presentations of girls with autism was also raised. While many girls with autism have different behaviours to the stereotype of autistic male behaviour (eg masking or camouflaging their traits or focusing on being socially 'accepted'), not all girls act in this way. It was highlighted that it is therefore important not to slip into the formation and continued use of female stereotypes for girls with autism.

Both an MP and a councillor shared their experiences of autism support groups in their areas and stated that families with autistic girls were not participating. This, they suggested, demonstrated that there is a hidden community of families who are not accessing mainstream support.

The important role of schools and teachers was discussed. Cheryl Gillan MP, Chair of the All Party Parliamentary Group on Autism (APPGA), reminded the group that the Government has committed to introducing teacher training on autism in the teacher-training programme for 2018 and that this could be a significant opportunity for building

understanding about autism in girls as well as boys. However, it was noted that, ideally, the training should also be offered to existing teachers retrospectively.

The meeting heard from Jane Friswell, who has been trying to get a better understanding of the link between girls on the autism spectrum and school exclusions. She outlined her concerns that there is likely to be a high correlation (although data collection is poor) and that the under-diagnosis and misdiagnosis of autistic girls may well be having a significant and negative impact on their education and future life chances.

When turning attention to the opportunities for progress, it was agreed that more money is needed to focus on girls with autism, for research, training and data collection – although attendees recognised that this is a difficult ask at a time of financial pressures across health and education.

More immediately, it was recognised that NHS England has prioritised learning disabilities, autism and mental health, and that these should be used as a lever to engage with senior government and NHS stakeholders. The NHS is in the process of developing a new pathway for lower level access for learning disability and autism services, which could also be an opportunity to further highlight the specific needs of girls on the autism spectrum. It was flagged that local government, while under considerable financial strain, is often interested in improving prevention and early intervention, particularly if it can lead to savings in the longer term.

The meeting concluded with Baroness Hollins stressing that there is still much to do to bring this issue into the mainstream. She, alongside members of the ASC and Girls Forum present, encouraged attendees to reflect on what more could and should be done to change perceptions of autism, girls and their families, and how key institutions, workplaces and offices of state can see this issue as the next big barrier to be swept away.

For more information about the ASC and Girls Forum please contact Julie Collick at the National Association of Headteachers at [julie.collick@naht.org.uk](mailto:julie.collick@naht.org.uk).

Girls on the Autism Spectrum: The Big Shout conference is taking place on Friday 27 January in London.

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